Chapter 1
Caregiver burden in relatives of patients with schizophrenia – reality and methods of support

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Abstract
Schizophrenia is a chronic disease that affects about 1% of the population. Scientific interest in the families of sick people has been rooted in the search for systemic factors affecting the onset, course and prognosis of the illness. Today, more and more attention is being paid to the role of the family as a source of support in the treatment process, and family cohesion is considered a positive prognostic factor. A person with schizophrenia often needs accompanying in the recovery process, therefore the patient's relatives can be a source of instrumental and socio-emotional support, often providing motivation for treatment and rehabilitation. Still, in the public health system the opportunities to support the patient's family are relatively small and limited to single initiatives. At the same time, research results and clinical experiences suggest that caregivers often feel overwhelmed by daily duties, feel a lack of reliable knowledge, and it is difficult for them to adjust themselves to their new role. This chapter provides scientific reflection on the consequences of caring for a person with schizophrenia. The state of the study and the possibilities of holistic support for the patient and his family system are analyzed.
Key words: schizophrenia, caregivers, burden

Introduction

The family is an essential part of the treatment of mentally ill persons. It is estimated that mental illness has a significant impact on patients themselves and up to 10 people in their surroundings [1]. The illness of a relative always makes it necessary to reorganize roles, responsibilities and habits. Just as sick people learn to adapt to the new situation, family members look for new forms of communication and try to find a balance between concern and demands, care and freedom. The appearance of mental illness in a family is a challenge and requires internal reorganization. Although the original characteristics of the family (pre-crisis history, consistency, coherence, individual characteristics of all family members) are of undoubted importance, families often do not receive appropriate support from medical staff and therefore search independently not only for information about the disease and treatment, but also for support with their own problems. Research supports the thesis that interventions targeting the patient's family can have a significant impact on treatment outcomes, including the length and quality of remission [2].

Caregiver burden

In most cases, a person who takes care of a mentally ill patient belongs to their immediate family [1]. Studies among families of people with schizophrenia shows that caregivers are mostly women, most of whom live with the sick person and perform professional duties in parallel. In almost half of cases, the patient's caregivers were parents, followed by husband/spouse. A caregiver often feels (and usually is) responsible for taking care of the patient's household duties and needs, monitoring his mental state, detecting early relapse signals, and verifying the regularity of medication and medical checks. Caring for a relative with mental illness also requires real financial costs [3]. In the case of a heavy load, the caregiver often feels a kind of burnout in this role that is manifested by a feeling of fatigue, helplessness, and often anger towards the sick person.

Although the concept of caregiver burnout originally applied to those in a professional role [4], contemporary research clearly shows that family members of people with disabilities suffer from burnout symptoms that are comparable to those experienced by professional caregivers [5]. The sense of emotional exhaustion not only negatively affects the quality of life of the caregiver and is a risk factor in their own mental problems, but it also triggers negative defense mechanisms and can negatively affect their involvement in care.

The impact of a relative's disease on the functioning of the family (e.g. reduction of economic status, limitation of leisure opportunities) is referred to as "caregiver/family burden" in the literature [6–10]. These consequences are generally divided into two basic categories:

- Objective burden – directly related to the severity of symptoms, the duration of the disease, and sociodemographic variables (age, gender, level of education, degree of kinship). These relate to real changes in the functioning of the family (increased duties, change in professional activity, deterioration of the caregiver's health)
- Subjective burden – the mental functioning of the caregiver, including a sense of tension, despondency, loss of something important in life and even anger.

Based on interviews with caregivers of people with schizophrenia, Gater et al. [11] categorized the basic areas affected by the experience of care. In the caregivers' narratives, they found the following threads:

1) Emotional Impact – the issue of emotions experienced due to the burden of care was discussed in interviews most often. The subjects described feelings of overload, sadness, helplessness, frustration, embarrassment, anger or stress, but they also reported severe and disturbing mood swings.
2) Caregivers' Concerns – mostly related to the course of illness and its impact on the patient's functioning. Caregivers often wonder how their role will look as the disease progresses.
3) Impact on Daily Activities – for many of those surveyed, caring for a person with schizophrenia had become a central part of their life

that marginalizes opportunities and needs related to leisure and social relations. It is worth noting that primary caregivers feel alone in the performance of their role. In such cases, the disease may influence other relationships within the family.

4) Physical Impact – caregivers often observed a concrete impact of the burden on their own health. They not only felt worn out and tired but also reported an increase of chronic physical symptoms. This may be related to stress level, chronic anxiety and real physical demands.
5) Financial Impact/Impact on Employment – in most of the studied families, a person with schizophrenia was more or less financially dependent on others. As a result, caregivers reported decreased financial status, less productivity due to the burden and, in some cases, the need to give up work.
6) Impact on Relationships with Others – caregivers saw the disease as disrupting their relationships with loved ones and the wider social environment. They declared they had only a small amount of time that they could devote to other family members; they also reported social isolation that was compounded by the stigma phenomenon. Many studies still indicate that caregivers of mentally ill people experience stigmatization in the area of social contacts [12–14]. In the studied families, most relatives felt isolated and responsible for the patient's illness. They reported getting negative feedback not only from the widely defined social environment but also from medical staff. Such experiences are a source of shared stigma. The persistent sense of guilt and shame about the disease that is shared by relatives makes the family procrastinate with the search for help and shut out the external environment, which often has a negative impact on the patient's health and recovery process.
7) Impact on the Relationship with the Person with Schizophrenia – taking into account the negative aspects of the relationship between a caregiver and a person with schizophrenia, families often mentioned aspects related to denial of the problem and the need for continuous monitoring of treatment. Relatives often described this experience as

a kind of struggle that drained their strength and permanently violated mutual trust.

Factors leading to caregiver burden

Polish studies of families of patients receiving stationary psychiatric treatment are consistent with previously described results. They show that the care burden affected most subjects, most of whom declared frequent concerns about the patient's health, safety and future, as well as the burden of constant efforts to motivate him to be active. As many as 67% of the surveyed caregivers experienced a real deterioration in their health [10]. Caregivers of mentally ill people, due to high stress levels, are at risk of developing depressive and anxiety symptoms.

Although studies do not allow the creation of a uniform matrix of the factors that affect the burden of caregivers of people with schizophrenia, on the basis of qualitative studies many authors are attempting to classify the most important ones [15–17].

It seems that the burden of care should be related to the course of the disease itself. Although some studies confirm this relationship, it is unclear whether this applies to positive and negative symptoms or to the general level of functioning [16]. It is possible that both of these factors have equal meaning. The severity of symptoms can directly affect the difficulty of providing care as a result of disrupted communication and behavioral disturbances (e.g. aggression). Families report the weeks before hospitalization as the most overwhelming period in the care cycle of the sick person [17]. Inefficiency and isolation can make it necessary to assist a sick person in fulfilling even basic life needs. It was also revealed that high levels of stress and burnout among caregivers were related to patients' poor response to treatment [15].

Researchers have attempted to analyze the type of relationship between the patient and the caregiver as a determinant of the care burden. The results in this area are inconsistent but indicate that the highest burden falls on patients' parents and spouses [18–20].

Caregivers who feel overwhelmed by their everyday struggles often present inefficient ways of dealing with the crisis. Among them, avoidance, denial, coercion and negative distraction dominate [21–24]. Scientists pay special attention to relatives' appraisals and their role in caregivers' burnout and patients' recovery processes. It was revealed that caregivers who appraise the illness more negatively tend to report a greater burden and stress level [25]. Negative cognitive appraisals may result not only from depressive symptoms, but also from lack of knowledge and experience. They may be especially visible when the symptoms of schizophrenia first occur [26]. It seems to be especially important to support families from the beginning of the care process in order to help them find a sense of their role in the patient's recovery and inform them about possible positive outcomes and prognoses. Surprisingly, single studies suggest that active and problem-focused coping strategies may be related to greater burnout among caregivers [27], thus increasing helplessness when there is insufficient support.

Positive outcomes

In the psychiatric literature, the concept of 'burden' is increasingly being replaced by more neutral terms such as 'consequences of care' or 'care experience'. This is done to highlight the multifaceted experience of the crisis of a family member's mental illness and its impact on the whole family system. In various studies, positive outcomes of care have been mentioned by caregivers [9]. They reported that such an experience can lead to greater sense of living, love and a deeper relationship. It must be noted that with appropriate support, caregivers may experience post-traumatic growth which leads them to evaluate their experiences positively [28]. It is not surprising then that positive outcomes from the patient–caregiver relationship are correlated with social support, optimistic and problem-focused coping mechanisms, and personality traits such as openness to experience, extraversion, conscientiousness, and agreeableness [29]. These results support the role of various intervention programs developed for

schizophrenia caregivers in order to help them manage the crisis of mental illness and the burden of care.

Methods of support

The problem of family experiences when caring for schizophrenic patients is a universal challenge in all countries. One of the main and most widely available forms of support for caregivers of mentally ill people is psychoeducation [30], which should focus primarily on equipping relatives with the most important information on mental health and its dysfunctions. Most often this takes place in thematic sessions and involves a discussion of various types of disease, their symptoms, as well as prevention and diagnosis of relapse signals, treatment options and costs, including the effects of pharmacotherapy. This knowledge allows caregivers to feel safer and more competent in their roles, and also, among other things, it realistically supports the treatment process by more effectively recognizing the signs of deterioration of the mental health of a close person [31]. Furthermore, it is useful to equip families with skills related to coping with stress and methods of reducing it (e.g. relaxation techniques) [32].

Caregivers of persons with mental disturbances often struggle with a sense of misunderstanding and alienation that makes it difficult for them to seek support and meet their social needs. The literature draws attention to the important role played by support groups for families of people with schizophrenia [6]. Both reports from scientific literature and practical experiences of working with relatives of mentally ill people suggest that the experience of participating in a support group builds a sense of belonging, understanding and acceptance. In addition, caregivers of mentally ill people learn ways of communicating and finding a balance between providing support and allowing the patient to be autonomous and make mature decisions. Sharing their own experiences reduces tension and is a source of hope. This form of support facilitates the process of adaptation in the face of the diagnosis of the mental

illness of a family member. It is also helpful for sustaining remission and dealing with everyday difficulties, as well as meeting the social needs of people who deal with mental illness in their family.

Research shows that family support is a factor that positively affects the treatment process of psychiatric patients [33–35]. Relatives may play an important role in supporting the patient's self-esteem and building their hope in a positive response to treatment and a return to everyday life. At the same time, they are a source of security that provides support during crisis periods and offers a safe space for rebuilding self-reliance and preventing the creation of a stigma-based self-image.

Lack of or inadequate support from relatives can hinder the treatment process, including shortening remission periods, non-compliance with medical recommendations, or lack of motivation to build self-reliance. In psychiatric treatment, the best results are achieved when the patient, doctor and family work together towards a successful recovery. Due to these benefits, attention should be increasingly paid to efforts aimed at implementing multifaceted family support in psychiatric care.

Measurement of caregiver burden is a process that is usually not included in the formal diagnosis of a patient's situation, for example on psychiatric wards. However, due to the fact that family well-being is an essential factor in a patient's recovery, standardized measures of caregiver burnout should be one of the main parts of the diagnostic process as they help to get a broad picture of the current situation and its future potential for rehabilitation purposes.

Conclusions

Schizophrenia, due to its course, is a disease that is considered a serious crisis for the family. Various studies reporting caregiving experiences may result in advantages for the development of the treatment of mentally ill people. This need is consistent with actual trends in psychiatry which encourage taking care of patients in their own environments and reducing the risk of acute states and hospitalizations. Although the

caregiver's burden is a fairly universal aspect of family relationships and seems to be observed worldwide, there are cultural differences that relate to the social perception of mental illnesses and methods of help. Further research in Poland is needed to explore family–patient relationships and the effects of a family member's mental illness on treatment results and quality of life.